

The Lewin Group

Supporting Family Caregivers of Older Adults through Times of Stress and Isolation: A Panel Discussion July 16th, 2020 – 3:00pm EDT

Alana Nur: Thank you, and welcome, everyone, to the webinar Supporting Family Caregivers of Older Adults through Times of Stress and Isolation, a panel discussion. My name is Alana Nur, and I'm with the Lewin Group. Today's session will include a 45-minute presenter-led discussion, followed up with 15 minutes for question and answers. The session will be recorded and we'll be posting a video recording, along with today's slides, at resourcesforintegratedcare.com. The audio portion of the presentation will automatically stream through your computer. Phone lines are also available. You can access the number by clicking the black phone icon at the bottom of your screen.

In April, we held a highly attended webinar on this topic of Supporting Caregivers of Older Adults through Times of Stress and Isolation. Thank you so much to all of you who attended or viewed our recording. As we received so much interest in the topic and it continues to be so important at this difficult time, today's webinar continues our discussion, and addressed topics requested by participants from the first webinar.

Before we continue the discussion, I wanted to note that if you were not able to join us or view the recording yet, please visit the Resources for Integrated Care website, where the video replay is posted. As a programming note, this webinar is supported through the Medicare & Medicaid Coordination Office at the Centers for Medicare and Medicaid Services. MMCO is helping beneficiaries dually eligible for Medicare and Medicaid have access to seamless high-quality health care that includes the full range of covered services in both programs. To learn more about current efforts and resources, please visit our website or follow us on Twitter for more details. Our Twitter handle is [@Integrate_Care](https://twitter.com/Integrate_Care).

All right, at this time, I'd like to introduce our moderator. Carol Regan is a senior advisor to Community Catalysts Center for Consumer Engagement and Health Innovation and has over 30 years of experience with national and state-based public policy and advocacy organization. Carol?

Carol Regan: Thanks, Alana. I am--move the next slide--I'm really pleased to continue this discussion with some of our nation's leading experts on the front lines of providing support to family caregivers. I'm gonna start with the introductions, and then we can do some polls, and we can review the objectives, too. But let me start with introducing the faculty.

So, Kathy Kelly is the Family Caregiver Alliance executive director, and she oversees programs in the Bay Area California Caregiver Resource Center, providing direct services to families in the San Francisco area. And she's very engaged in a lot of

California policy collaborations and the National Center on Caregiving. During Kathy's tenure, the organization has grown from a grassroots program to a very well-respected national organization that provides leadership on supporting family caregivers with best practice interventions, public policy, state system development, and leading-edge research.

She represents the agency on a variety of national coalitions that work toward including family caregivers as part of the care team. Kathy has written and lectured about caregiving, public policy, and system develop [sic] and the use of consumer technology, which you'll hear a little bit about today. We're delighted Kathy is back with us.

Our next speaker would be Dr. Erin Emery-Tiburcio. She's an associate professor of geriatric and rehab psychology and geriatric medicine at the Rush University Medical Center in Chicago. She's a fellow of the Gerontological Society of America, the past president of the Society for Clinical Geropsychology, and past chair of the American Psychological Association's committee on aging.

Currently, Dr. Emery-Tiburcio co-directs the Rush Center for Excellence in Aging, and Catch On, which is the Health Resources Services Administration-funded geriatric workforce enhancement program at Rush. We're delighted that Erin is back with us.

And then our final speaker, our last speaker, is Bryan Godfrey. Bryan completed his undergraduate coursework at Indiana University in Pennsylvania, and received a master's of arts in publishing and writing from Emory College in Boston. And then after several years of teaching English and cultural diversity, he moved on to get his second master's degree in social work from the University of Pennsylvania. He became a licensed clinical social worker and he spent the next four years providing outpatient psychotherapy for underserved adults in north Philadelphia.

Ultimately, Bryan moved to North Carolina for his current position at the University of North Carolina geriatric specialty clinic, where he serves patients and their caregivers as the clinic's only social worker.

So you can see we have an incredible group of people to answer your questions and to provide feedback. So we'll turn to the next slide. Great. And so just recap the learning objectives for today. We want to identify some strategies for addressing depression and emotional health, which we've heard a lot about from many of you and the other participants in the last webinar.

Identify strategies, concrete strategies to help caregivers and their families cope, particularly in the stress of uncertainty and the transitions that are going on now with the public health crisis. And then identify ways to help you all identify the community resources needed to support these families. Thank you, next slide.

So this is briefly what we're covering. We'll have some polls, we'll talk about supporting caregivers through this panel discussion, we'll have questions and answer session from you all. And then at the end--and this will also be posted on the website--we'll have

resources for you to carry you forward in your work, and we'll ask for a short evaluation. Great, next slide.

So as always, we really wanna hear who you are, so we can address the comments you have, and the audience. So if you could see this poll, what's the best--the following best describes your professional area. And again, it may be overlapping, but just choose one--health plan--case manager care coordinator, you're in pharmacy, social work, administration, medicine.

All right, couple more seconds. Good, okay. Let's see the results of who we have on the phone. Ah, this is very common. Thank you, it's great to have so many care managers or care coordinators, a little under half. We have some people with administration and management, some providers, and social work, great, great--and advocacy. Great representation of social work, terrific. Okay, and the next slide--we'll do one more poll.

In addition to your professional area, we're really interested in knowing a little bit about where you're working. What type of organization. Let's see if that can come up. Okay, great. So if you can answer, again, the setting--it's a setting, it represents where you work, a health plan, ambulatory care setting. You can see the choices here, several of them--research, consumer organization.

Great, just a couple more seconds. Okay, great. Let's see the results of who's on the phone. Again, oh, almost half in a health plan, that makes sense. And community-based organizations, wonderful. So many people who work with family caregivers and long-term care, great.

Wonderful. All right, thank you. So now, to start off our webinar, we're just gonna do a short opening, and let me turn this over to Kathy Kelly to set the framework for today's discussion. Kathy?

Kathy Kelly: Thank you, Carol. You can advance the slide. So this is the second webinar, as mentioned, that Erin, Bryan, and I have had the pleasure to present. The first session was held in late April, and I think for most of us, the presenters and also folks that are on the phone, we were really at sort of the beginning of our experience with service delivery during the time of COVID.

I think it was safe to say that we were basically all in sort of a crisis mode at that time. So as we were asked to return to discuss the issues that we were not able to cover then, we wanted to acknowledge that there are number of changes that will be with us for a while, and these issues are affecting family caregivers. And for those adults with dementia or other chronic care conditions, and for the provider community, we're all in this together.

So there's a number of intersecting issues for family and friends during this time of uncertainty, and the increased anxiety on the part of caregivers. And we wanted to set a little framework and context for where we all have landed at this particular moment. In the health area, we still have high safety and protection needs at this time, not only for ourselves, but those that are higher risk in our families, by age or chronic health

conditions. Others that are in the household or still may be working outside the home, and they're in contact with the public.

So the fear of infection and uncertainty around testing and care--and when I say "care," it's just not COVID-related, it's other routine or specialty care that's ongoing--it's an uncertainty around the safety issues that still will present themselves. We also have no clear end date to resume activities really available, so there's really no certain timeline for when a future vaccine and treatment for COVID will become available. So we have a little bit of anxiety around that as well.

And then as we know more about COVID and how it may change, the kinds of recommendations for physical distancing and other guidelines may also change as we learn more about the disease. I think we basically know that we all need to wash our hands, not touch our face, wear masks, and keep our surfaces and everything clean. But I think some of these things may be more important than others, and this is what we're learning.

Also affecting our context right now is the effect on the economy. We had inklings of it a few months ago, but we really know now that there are huge budget challenges in state and localities that may threaten some access to services. It's safe to say that state budgets are a bit on the chaotic side at this point. And then we do have the impacts of unemployment and economic recession that looms large in the future. All of us will be affected, but certainly budgets for these kinds of programs that we're talking about today.

So we're also asked to be doing planning in the time of uncertainty within resources and services that are available, and I think this is trying to get your hands around and being in control of certain aspects of your daily job considerations. But for families and caregivers, this loss of control is really significant.

So I would say in summary that communication is the key. It's the direct, correct information that's being provided to the caregivers, and secondarily I want to--you know, second the communication within your community of providers, whether it's across public health, healthcare, social services agencies, community-based organizations, transportation services, and others. Having the communication on an ongoing basis ensures that you in turn can give the correct information to families. Thank you.

Carol Regan: Great, thanks, Kathy. Okay. So, now we're going to move into a panel discussion offering some scenarios that we've learned about from many of you in the field, and wanted to talk about that with the faculty. So the first scenario I want to raise is an example of a woman named Vanessa who is a middle-aged adult who's been living with and providing--we've put the scenario up on the screen so you can see it--regular household support for her mother, who has diabetes and hypertension. She's been doing this for a couple of years.

But she lost her job as a restaurant server due to COVID, and so she and her mother have relied on unemployment benefits and SSI, and Vanessa's not sleeping or eating well. Her

physical health has declined. She wants to resume working, but she worries about bringing the virus home. Probably a very common thing you all hear.

So, let me turn this over first to Kathy. How would you approach a conversation with Vanessa about ways to attend her own emotional and physical health and supports?

Kathy Kelly: Well, you may have to consider strategies for helping Vanessa find assistance. And this can be done directly by conducting an assessment to first see if her mother is eligible for any additional services, particularly at this time. There is increased services around meals and other consumable supplies that might be available, and housing support.

Carol Regan: Right.

Kathy Kelly: And also, Vanessa should be looking at all of the unemployment or extended benefits that she might be eligible for too.

Carol Regan: That's really helpful. And Erin, do you wanna also address this, in terms of how would you approach this conversation with her?

Erin Emery-Tiburcio: Absolutely. I think in addition to the formal resources that Kathy so beautifully laid out, I think I would encourage her to recognize the resources she already has. So we talked last time about the critical nature of physical activity and exercise and socialization in taking care of herself and being able to kinda take care of her own basic health needs.

Certainly as a psychologist, just about anybody who comes to see me, we talk about physical activity, we talk about diet. And eating junk food and loading up on alcohol is what a lot of people are doing right now, and gaining the COVID 19. And so the degree to which she can take care of herself is critical in this regard, and so folks on the call might ask is there anybody who can help you, do you have family members or friends or neighbors who might be able to help with your mom, as well as for her own support.

Carol Regan: Right, that's helpful, because I think sometimes people don't think about maybe reaching out to other folks. So encouraging them to ask for help, that's really helpful, Erin.

So let me offer another scenario. We'll switch to someone named Juan. Juan is a widower. He has macular degeneration and emphysema, and he lives at home by himself. Due to his health--in Arizona. Due to his health issues and limited English proficiency, he relies on help from his oldest daughter, Maria Elena, who does not live in the same community. She lives in LA. So she helps with his medical care, his appointments, she communicates with his health plan and his primary care provider. For those of you who work at a health plan, you'll recognize this. And she does more for him. She used to travel monthly to handle her dad's care, but COVID-19 has meant she's had to juggle this from afar.

So a question to pose to all of you is what recommendations do you have for Maria Elena as a daughter who's providing care from a distance. Even people, maybe you've experienced people who live in rural communities, who aren't close to folks. What recommendations do you have for them? And I think I'll start with you, Bryan.

Bryan Godfrey: Yeah, definitely. This is a very common scenario nowadays, where the person who is maybe even the primary caregiver for the individual doesn't live with them and might not even live in the same state. And they'll go through remarkable means, like traveling across states, to provide the support that's needed. And in this case, we have a language barrier on top of everything.

Carol Regan: Mm-hmm.

Bryan Godfrey: So of course the first thing we're gonna do is do the assessment that we're always doing in what kind of needs are present here, and what kind of strengths does the person have. In particular, it can be easy to discount someone who doesn't speak the dominant language as not having strengths or not being able to communicate, and even family members can assume that, when they might actually have more ability than we think.

The other thing is we might be relying on only one or two people, when in fact there's other people or other groups out there that might be able to provide support. So we need to be aware of what the local resources are, especially for folks that speak Spanish, and see if we can link the patient and the caregiver with these resources.

Is there some kind of a volunteer program, or, you know, any other sort of program where there would be Spanish-speaking support in the community? Or is there even a doctor's office that has individuals who speak Spanish. Or if we have to, to rely on a translation service. Lots of options where Juan can actually advocate for himself to get that translation service, and Maria Elena can provide some support at a distance, rather than having to travel there physically.

Carol Regan: That's really helpful. Kathy, how about you? Do you have recommendations, things you want to share?

Kathy Kelly: Oftentimes, the oldest child does get trapped into the role of managing the parents' health and activities, and sometimes, the siblings are just fine with that arrangement. But in this case of being a long-distance caregiver, I think we really want to talk with Maria Elena to find out whether or not there are other siblings that live closer by who might be able to help with the task.

And this is normally not something that's top of mind, but I think I would mention it too-- that she's making a lot of arrangements on the medical side, and to make sure that she is familiar with the patient portal within the health system. That might help expedite some of these tasks, such as making appointments and refilling prescriptions by mail and so on.

And, you know, I echo the sentiment that rural areas do not have as many formal services available, but there might be other support services in churches and civic organizations,

even though libraries and school community service programs. I realize these may not be available at this time, but sources of support come from surprising places--

Carol Regan: Right.

Kathy Kelly: --in rural communities.

Carol Regan: Right. So casting a wide net for those serving this population. That's helpful. Erin, how about you?

Erin Emery-Tiburcio: Yeah, so I would add on to what Bryan had mentioned about a Spanish-speaking care coordinator or companion. He happens to live in Yuma, Arizona. Yuma's 50 percent Hispanic, so in all likelihood there are some other folks who may be bilingual--a neighbor, perhaps, who may be able to help out, as well.

And then too, Kathy mentioned having access to the patient portal. I actually wonder if Juan could--or already knows how to use a tablet or a smartphone. It's possible with FaceTime that his daughter might be able to virtually go with him to appointments.

Carol Regan: Mm.

Erin Emery-Tiburcio: I've had family members join in to appointments with me, both virtually and in the clinic, and perhaps an Alexa-type system that Maria Elena can set up in the home, that would allow her to check in on her dad through a voice system. So if technology was too complex for him, she might be able to set it up for him, and be able to check on him without his needing to be able to press lots of buttons. So there are a lot of technology options with regard to that.

Carol Regan: That's really helpful, very helpful, concrete suggestions from all of you, thank you. So let's move to one more scenario before we open it up to have some questions. So June is a 75-year-old woman whose husband is 85, and he has dementia. Last year, he fell, he hit his head, and he had a head injury.

He recovered physically, but his cognitive ability was such that June couldn't take care of him at home anymore, so she placed him in a dementia unit last summer. And since then, she's really struggled with sort of the grief and guilt of that choice for months. She used to spend hours with him daily at the facility and help with his care, but now with COVID-19 she hasn't seen him since March, and she's really feeling depressed.

She talks to him on the phone every couple days, but she's still grieving the situation. Still, the question to you is how can care managers or care coordinators or providers who are supporting June and her husband, what can they do to help June cope? Let's start with you, Erin.

Erin Emery-Tiburcio: Sure. So last time, when we talked a little bit about coping during COVID, we talked about the idea of identifying what's in your control and what's out of your control. And it sounds like June is feeling guilty about a lot of things that are outside of her control.

She can't visit her husband, and that is not her fault. And so being able to identify what she can control and what she can't control, and being able to let go of some of that guilt. And at the same time, since she's spending less time with him day-to-day, it might be a great time to think about her own grief.

So, losing someone with dementia, bit by bit by bit over the years, is an ongoing grief process, and it can be excruciatingly painful, because it's not only what you're losing day-to-day, but also what you anticipate losing. And then she lost this time with him. So she may be able to take this opportunity, now that she has more time to herself, to move through the tasks of grieving.

And there's a great resource that Alana will post and make sure that you all have on the tasks of grieving on our [Rush] CEO website. There's a video for people who are grieving, and there's some guidance to help people through the tasks of grieving. So once she's able to better manage her own grief, it's possible that when she is actually able to see him again in person, she may be in a better place and better engage for him.

So recognizing that even when you've got someone--when you've placed a loved one into an assisted living or a nursing home facility, caregiving doesn't end--

Carol Regan: Sure.

Erin Emery-Tiburcio: --for many of those folks, and so being able to be sure that you're attending to those needs, as well.

Carol Regan: Thank you, Erin. And Bryan, I'm sure this is a common situation that you've encountered, too. Would you mind sharing some of your thoughts on this?

Bryan Godfrey: It is indeed a common situation, and I really just wanna echo what Erin was saying about what I like to call the two G's--grief and guilt. They are the two biggest emotions that I find a lot of caregivers going through, especially during times of transition for a loved one.

So I think first off we need to label what these emotions are--that this is grief and this is guilt. Oftentimes, grief in particular is hard for us to wrap our minds around, because the person hasn't actually died. But any time there's a loss, people can experience grief, and I do think that's taking place here.

So validating these emotions as what they are, giving them a name, making sure that people know these are normal, and some people don't need any support for that, they're fine, and other people do, and there's nothing wrong with that either way. I think most people would benefit from having some kind of support, and we can normalize that, too.

So we can look at June's strengths, we can look at her resources and see where can we meet her needs. Is there counseling available through her insurance, is there maybe an activity that she's been wanting to do that she's been putting off. Maybe there's a local support group she would enjoy connecting with, or something else entirely. Just something that's right for her, to try to process those emotions that she's feeling.

And the other thing that Erin also mentioned is this connection doesn't end, even though it can feel like it does at some point. If we're not able to interact with someone physically and give them a big hug, that's painful, especially when we're used to doing that. You know, so again, validating that for the person, and then focusing on the need to do something that still connects, but in a different way. A lot of people are saying that it's not social distancing, it's physical distancing, and we need to remember that.

Carol Regan: Yeah, yeah.

Bryan Godfrey: How can we connect socially, even though we can't physically connect? So maybe that would mean a video call. Maybe that would mean calling the staff to get an update now and then, and really advocating for what this person needs. Maybe it would be about finding a safer way to meet in person, like meeting through a window or meeting in an outside space. It may seem silly, but it's a powerful way for people to connect to someone when they feel like they have no other way.

Carol Regan: That doesn't sound silly at all. Sounds like really wise advice. Let me bring you into this conversation, Kathy. What do you think? What are some of the ideas? I'm sure you, again, have a lot of experience with the organization you're with to help address this.

Kathy Kelly: Yeah, I think I'd just like to echo what Bryan has raised about support groups, and a bit of advocacy, instruction on advocacy, to have access to have meetings either through video chats and so on. And support groups are--many of--all of them are now meeting by either phone or by video chat, so to make them more accessible to everybody.

And I would urge, if you're looking for who's doing what, to call either 211 or the area agency on aging in that particular community. I just parenthetically had a work colleague of mine on the East Coast mentioned that for the first time in over four months she finally was able to see her mother, and did exactly what Bryan had mentioned, which was the facility did arrange to have a meeting through a glass door. The door was closed, obviously, but she was able to see her mother for the first time in four and a half months. And it was--it just calmed the situation down significantly.

Now, I want to say that when we are dealing with nursing homes, if you happen to be in a hotspot for COVID, it's a very tense time. So there may or may not be this kind of access or time available, depending upon what's going on in the nursing home, to be able to facilitate these kinds of arrangements.

But by pushing a little bit, I think the family would be very surprised that they would be able to access information about how their relative is doing, if they just did a bit of advocacy on that account.

Carol Regan: Great. Very helpful. Let me turn to another question that's come up a lot in both last webinar and from what we're learning. What advice do you have for helping a family caregiver support an older adult who's depressed? So we talked a little bit about it

earlier, and Erin and folks talked about this. But let me again turn to you, Erin, for some advice on what you would do to help this caregiver.

Carol Regan: --the person they're caring for is depressed.

Erin Emery-Tiburcio: Yeah, well, so a couple of thoughts. One is to make sure that it's depression, because certainly a number of physical and emotional issues can look like depression, so wanting to make sure that there's a clear medical diagnosis of depression. And if that's the case, then at home, one can, again, as I mentioned, encouraging physical activity, appropriate diet, appropriate sleep, trying not to do too much daytime napping, which can happen a lot with depression.

Increasing social engagement, which, again, as Bryan mentioned, socially connected, physically distant. And anything that they used to enjoy. Engaging in activities can help behavioral activation, can help counter depression, and also acknowledging that energy and interests might be barriers, and can be rather challenging, so being assuring that you are patient and encouraging, rather than blaming. I think the other thing to be aware of us we talked a little bit I think last time too about depressive contagion. So if you are around someone who is depressed a lot of the time, it can be rather depressing. So assuring that the family caregiver is taking care of themselves, and making sure that they're also spending time, virtually or otherwise, with people who are not depressed, to minimize that likelihood of contagion.

And then if possible, see a mental health professional. There are so many opportunities to do this virtually now that it makes it so much easier. You don't have to worry about getting the person up and dressed and out of the house, that you can do that right in the home and potentially have a really helpful consultation with someone who you may not have had access to before. I know I'm getting a consult for my dad with a geriatric neurologist in a different state, because we can right now.

Carol Regan: Right.

Erin Emery-Tiburcio: And this is a great opportunity for people who may not have access to a geriatric mental health provider in their neighborhood. But my gosh, you can access one from anywhere right now.

Carol Regan: Sure.

Erin Emery-Tiburcio: So, one of the up sides of COVID.

Carol Regan: Yep, thank you. Bryan, how about you? What do you--how do you--

Bryan Godfrey: Yeah, my goodness, it's such an overwhelming situation when you're already a caregiver, you're already providing a great deal of support, and now the older adult you're caring for is depressed as well. So really having empathy for the caregiver situation is important.

I think the caregiver needs to learn as much as they possibly can about dementia--or excuse me, depression--to help counteract some of the common myths that we have about this. You know, we often feel like people who are depressed just--they're not trying hard enough, they don't care, they're being difficult, things like this.

The truth is that depression is a very cruel condition. It actually takes from people everything they need in order to feel better. So for example, a wonderful treatment, as Erin mentioned, for depression and a lot of other mental health conditions is physical activity, exercise.

And guess what depression takes away from you? Your energy, your motivation, your sleep--anything that you would need to feel better, depression tries to steal that from you. So understanding that helps you come at this from a real point of empathy, where you can focus on getting the person the help they need and not blaming them for their own issues that they're encountering.

Carol Regan: Great, thank you. So let me turn now to just another question. So this comes up a lot, and there's probably a lot more people who are first-time caregivers. So what advice do you have for supporting people who may be first-time caregivers? Erin, you want to start us off?

Erin Emery-Tiburcio: Sure. So I think one of the key issues to begin with is just acknowledging you're a caregiver. This is really important, particularly for spouses or adult children who just it's my role, I am a spouse. I'm not a caregiver, I'm a wife. So acknowledging that caregiving role, so that they can begin to access resources that are available.

And when--you know, I think we talked quite a bit, and Bryan did such a beautiful job of talking last time about the importance of having an assessment to identify their needs. Maybe they need occupational therapy for helping older adults with dexterity issues, or physical therapy to help caregivers learn effective transfers from bed to chair.

So first acknowledging they're a caregiver, and then making sure that we have a comprehensive assessment of what might be needed for a caregiver, and for the care recipient.

Carol Regan: Sure, sure. How about you, Kathy?

Kathy Kelly: Well, I'd like to pick up on what Erin is saying about the assessment. I think this is really a critical piece, particularly for first-time caregivers, is to conduct an assessment that covers both the direct care for the individual that they may be caring for now, and planning issues such as legal and financial issues, and what eligibility may be in place for services for the person with the disability.

And self-care issues for the caregiver, looking at stress and depression and physical health and so on. You need to meet people where they are in terms of what is their concern today, but also to give them sort of an inkling of the things that they might want to be thinking about for the future as well.

One of the other issues when you're dealing with somebody who's a first-time caregiver--and first-time caregivers become caregivers in a variety of ways. Sometimes it's gradual and sometimes it's a very sudden kind of occurrence. But going back to just the hands-on care for just a moment, I did want to mention that there's a variety of videos that are directed towards and targeted for family caregivers, because oftentimes, you just don't know how to do a lot of the basic ADLs and IADLs in someone's life, and also medical tasks that you might be called to do.

And we put together some lists of video resources that can be used with caregivers. They're all vetted resources that have also follow-up information to keep about what the video is about. And so they're available, and they should be in the resource list for this day two. Thank you.

Carol Regan: That's helpful. Just one other follow-up question, Kathy, before I turn it over to you, Bryan. Who conducts this assessment? Does plan staff conduct also include not just the enrollee but also the family caregiver?

Kathy Kelly: It depends on the setting. The plan--if it's a health plan, the social worker may conduct this type of assessment that does have some questions that are to the caregiver. Depends on the program and the assessment that's used within a particular context.

In the community, for caregiver support services, it's usually sort of flipped a little bit, where the caregiver is the primary client for services like ours, and secondarily will ask questions about the person they're caring for, what's their functioning issue, the main kinds of health conditions, and concomitant kinds of behavior that's an issue for that particular person.

Carol Regan: That's really helpful, thanks, Kathy. And then Bryan, do you want to just add before we turn to the next question? You want to add advice you have for supporting people who are first-time caregivers?

Bryan Godfrey: Definitely. I mean, I feel like Erin and Kathy captured it well, that the first point is acknowledging that you are a caregiver, or if you prefer the term care partner. You can use either of those terms to search online and find other resources in the area, and you can also ask about those things at your local community supports.

Education is a big part of a first-time caregiver's life, learning about the person's diagnosis, learning about what they need and what they don't need, when to offer help and when not to offer help. So these are things we can kind of put on the caregiver's radar, that even though you may not always need to jump in and provide support right away, you can be doing this kind of assessment, or having this kind of discussion with your loved one, to figure out what's needed and when, and how to provide it.

And we want caregivers to understand that although it could be a sprint, it's probably not. You're probably running a marathon in many cases, especially with this COVID-19 thing. It certainly feels more like a marathon than a spring.

Carol Regan: Right.

Bryan Godfrey: So we need to be doing some planning for the future as well, and as early as possible thinking about some of the things that may happen down the road, some of the difficult choices and situations that we may encounter, and how we might approach them, and having that conversation with your loved ones so everyone can be on the same page.

Carol Regan: Right, thank you all. So let me just turn over a couple more questions before we open it to the audience. So, this has come up a lot, accessing supports and services are going to be online, as Kathy opened up our webinar today saying. They're going to continue online for some time, and access to technology can be a challenge for some families, particularly some low-income families who don't have access to the Internet or have tablets or whatnot. What can you do to make sure caregivers are able to use the technology they have access to, the necessary technology? So, Kathy, would you help us address this?

Kathy Kelly: Yeah, technology, it's good to remember that the majority of family caregivers do use some form of technology in their daily life, and we see that caregivers are really--the lion's share are between the ages of 45 and 65, understanding that caregivers come in all ages.

And this is going to accelerate, particularly as a result of COVID, in the area of healthcare, with telehealth encounters better accelerating at a bright pace. And I think it behooves all of us to make sure that everyone has access who really wants access, and that's a larger issue than we can individually solve. But we may be able to advocate, and also refer to the organizations that are involved in providing access for either low-income or older populations, so I'm gonna talk about that in just a moment.

So there is a learning curve if you are using technology. It's always good to be able to provide that information up front, send it out before you're doing an encounter, and make sure that they understand where to call and how to use the technology that you're employing.

It's also good if you know if there's--if someone is having a particular problem, if there's somebody else in the family that might be able to get help, just because of the in-person encounters are not going on as before, that we really have to rely on some secondary helpers in this situation.

We do have some information. We put it together for the first webinar, which is on low-cost Internet access--in other words, providing that Internet connection--and also ways in which you might be able to find lower-cost technology.

I have to say that senior centers have really been doing a lot of work in educating older adults on the use of technology by having these classes in the senior centers, and I think when you think about it now, most of those classes are online. So there are some programs that are really quite--who are trying to get quite inventive by having some drop-

in hours for--by phone, that people can talk to somebody about how they can get connected.

So you see that everyone is pivoting and trying to find ways in which to help people access those resources in their own home communities. And again, by calling 211 or the area agency on aging or even just directly some of the senior centers in your area, you may find that there's some of these resources that are out there that can point people to maybe even more local resources and initiatives that are going on in those home communities, so we can make sure that people do have access to the information that they need, including communication with their healthcare providers

Carol Regan: That's a lot, thank you. Actually, just before I turn to the last question, Erin, I know you've mentioned before, doesn't Rush have--haven't you all prepared some materials to help older adults learn how to use smartphones and things like that? So you've got some fact sheets and materials to help folks?

Erin Emery-Tiburcio: We do, and as of yesterday, the Rush Center for Excellence and Aging also just funded one of our occupational therapists, who's going to be creating some online modules for how to access telehealth, and in a number of different ways. And we'll be co-designing that material with older adults.

Carol Regan: Great.

Erin Emery-Tiburcio: So there are a number of resources, both sort of PDF version for people to access electronically, as well as a video version.

Carol Regan: Great, so people know that's a resource out there, great. So one last question--this has come up also. What are the key components to conducting a wellness or a sick visit over the phone or video? Telehealth has become increasingly important. Erin, I wonder if you could share a little bit with us about your experience and what you think is helpful to do this.

Erin Emery-Tiburcio: Sure. So, prior to starting your video visit or telephone visit, either one, making sure that you're prepared. It might be helpful when you first get started to script out some of your outreach calls, and making sure that you're thinking about how your members or your caregivers feel comfortable when you first connect. You know, making sure that you're clear about who you are, why you're calling, where you're calling from.

And then some really basic logistics that I learned from a colleague at Harvard who's been doing telemedicine now for years--some really common things that we might not think about. So if we think about it as lights, camera, action. So, lights--making sure that both you and the person you're speaking to are well-lit and wearing plain clothing and plain background as much as possible. It's amazing how much bandwidth for Internet gets taken up when you've got really busy patterns or a lot going on behind you.

Camera, making sure you're looking at the camera and not at your keyboard or your screen. It's kinda like when any of us have gone to the doctor and the doctor's typing

away and not looking at you, and you don't feel connected at all. So remembering to look at the camera, and making sure that you can see the whole face. I've had a number of patients who we start psychotherapy and I can see their forehead. So we have to make sure that the camera is tilted correctly for both you and for the person you're speaking to.

And then action--making sure that you're using your best bedside manner, paying attention to what else you see on the screen. So attending--so one of the beautiful things about being able to do a video visit is that you can see how is their hygiene. You might be able to get some glimpses into what their living room looks like. Are they cleaning it? Can you see any safety concerns, like loose rugs or chairs?

And one other key piece about this is considering privacy. So making sure that the person you're speaking to is in the most private place possible, and if they want other people in the room with them, that that's up to them. And so attending to those privacy issues. And I noticed that there was a question that came up in the chat about some doctors not having platforms that allow for multiple people to be present.

So I just wanted to make a really quick comment about that--there are some real creative ways that you can get around that. So for example, the platform that we use doesn't allow for an extra party, either. But we've had a family member who's on the telephone, on speaker phone, next to the older adult, or vice-versa, if you're doing work with caregivers.

So think about the number of different pieces of technology that may be in the room to be able to participate in those kinds of conversations. And again, lights, camera, action. The one thing I didn't mention is sound. We do sound checks on these webinars before each time, and making sure that your sound is effective and making sure that they've turned off their TV or radio or whatever else might be going on in the background, to the degree that they can.

Carol Regan: That's great. Lights, camera, action is something people will remember. Terrific, thank you all so much. And now I'm going to turn it over because a number of questions have come in through the chat, and want to make sure we have a little bit of time to answer those. So thank you so much, and let me turn it over to Alana, so you can moderate the Q&A.

Alana Nur: Thank you, Carol, and thank you, Erin, Bryan, and Kathy for sharing all this valuable information. We do now have a few minutes for questions from the audience. Thanks everyone who already submitted your questions, whether that was through the Q&A feature or through your registration forms. If you do have additional questions, please submit them using the Q&A feature. It's on the lower left of the presentation screen. You can type your comment and press submit to send it.

All right, so I'll get started. Erin, maybe I'll start with you for this question. We had a number of questions come in related to handling family tension, and tension between members of the same family who may be providing care. What recommendations do you have for balancing tension between family members or caregivers such as when people

have varying opinions on safety measures. Erin, I'll start with you, but Bryan and Kathy, you can also weigh in, too.

Erin Emery-Tiburcio: Yeah, so that can be a complicated situation, and I think it would be helpful to identify the roles of family members and if the older adults are capable of identifying the roles that he or she wants the--the children, as in most of the cases when there's family tension around that, but sometimes with the spouse as well.

And having a conversation about what the issue actually is and whose agendas may be getting triggered. So it may be that there's a safety concern about Mom driving, but the concern really isn't about Mom driving, it's the concern that the adult son wants to be able to use the car, and if Mom's driving, he can't. So seeing to the degree that you can identify agendas, to the degree that you can identify what's meeting the need of the older adult themselves, and if you can help to navigate what those needs actually are.

And a critical factor there is what matters most to the older adult in that situation, and is it possible that that person can--the care recipient can help to direct their own care, and can help to direct the family conflict as well. I think identifying whether we're talking about a longstanding conflict of, you know, it's always been Bobby against Suzie, and no matter what Bobby says, Suzie's going to pick the opposite.

Or you're talking about two people who are really invested in providing the highest quality care and have different opinions about what that is, and that can be a different situation to navigate. I'd be really interested in Bryan's response to this, since you do, Bryan, a lot more family work.

Bryan Godfrey: Yes, I certainly encounter things like this pretty frequently. In fact, a lot of times, I'm meeting with the caregiver and maybe not the patient at all, and oftentimes, there's different opinions in the family about what should be done or how it should be done, when it should be done.

And, I mean, I think you hit it right on the head that a lot of it comes down to past history. For example, I could think of a couple instances where there were two siblings, and one was providing the vast majority of the care; one wasn't providing any care at all, or very little, and there was resentment between them because of this.

But there's often a good reason for that, and in some cases, it's even things like childhood abuse or trauma, things in the past that are coming back up now. And kind of helping to explore those, looking at the past dynamics and relationships, seeing what's new, what's not, why is this being triggered in this way right now--if we can figure out some of this, then we might be able to find a way to move forward.

This can be very difficult to do on our own, and sometimes therapy or even some kind of family therapy could be helpful. But it might be worth exploring. Couple other things I've come across frequently--one is that there's trouble in the family accepting the diagnosis, especially if the person has some dementia and maybe other people in the family haven't had a direct experience of that, and maybe they have no idea what's going on at all.

So to hear that all of a sudden the person's freedom needs to be restricted just seems unacceptable to them. Sometimes they need to understand or even experience firsthand the person's impairment, so they can understand, oh, wow, we really do need some support here.

Another thing I've found to be particularly helpful is that siblings often don't want to be the bad guy. You know, they don't want to speak up to their parent, and indeed, it may be completely incompatible with their culture or their time when they were growing up to speak back to an elder or restrict their freedom in any way. So sometimes we need someone outside of the family to be the bad guy and really say this is what's needed, and here's why.

You know, maybe there's a specific safety concern, and we have to address this. Oftentimes, our doctors will say let me be the bad guy. Bring them to me, let's have this conversation, and if anybody needs to be mad at somebody, let's let them be mad at me, because at least I'm removed from the situation.

Alana Nur: Thank you so much, Bryan and Erin, those are great responses. Kathy, maybe I'll start with you on the next one. We did have a number of questions come in around caregiver burnout, so what kind of recommendations do you have for caregivers to avoid and address burnout, especially for caregivers who are now balancing full-time caregiving along with other responsibilities.

Kathy Kelly: I think we're seeing this more now, as we're entering an extended period of sheltering in place, at least in California. And we're getting a lot of requests for respite services now, even though there's safety concerns and issues. But the basis of the requests for respite and time away is because there is a lot of burnout that's happening with care that's being provided 24/7 without the benefit of having other kinds of--going to other kinds of community programs.

So it's really carving out that time for yourself and the parameters for being able to take a half an hour or even 15 minutes once a day to get out and take a walk or to do something that puts you more back into balance. But it's also working with the family caregiver in order to be able to articulate what their needs are, to say to other family and friends that may be involved in the care, this is what I need now, and make a direct ask.

And sometimes, we forget that it's hard to ask other people for help, and we always encourage that by trying to work with the family to articulate what it is that they do need, who might be in their care constellation in their community, if they can ask for that. Because oftentimes, people want to help, they just can't.

Aside from that, there's a number of different resources out there that will help with meditation. There's a whole lot of apps that are free to use. Other programming that's going on that offers activities--of course, this is online--but offers an opportunity to do an activity in partnership with the person that they're caring for.

There's a number of programs that are coming out of arts organizations that gives an opportunity for someone to be--for the person who you're caring for to perhaps be

involved in the program, but also be in the--the program is delivered in your living room, and you might have an opportunity to kind of get away for a few minutes and do your own self-care during that time.

So it's a struggle, because we don't have the usual and customary respite opportunities, but we can try to carve out those respite opportunities by using other kinds of means to do so.

Alana Nur: Thank you, Kathy. So I think we just have time for one more question. If you have any additional questions, please feel free and submit them here, and we will be working on a Q&A document later. So Bryan, I think I'll start with you on this one. This is an important one. Given the systemic racism and trauma faced by people of color, what additional considerations do you have for approaches to supporting caregivers?

Bryan Godfrey: Yeah, definitely. It's a pretty heavy topic, and I'm certainly not an expert on it, but I was doing a little bit of literature review before we got on the call, and I came across a meta analysis of 116 studies that found that people who are in an ethnic minority position tend to suffer lower levels of baseline health. Right from the beginning, they're over-stressed and under-cared-for.

And they often have to provide more care, but at the same time, they often have stronger familial obligations and better support networks, so they sometimes describe that care as being less stressful to provide. But then again, you also see studies saying the opposite. So it's clear that we need more research on this as a whole, and there's tremendous variability based on where someone lives, their socioeconomic class, and countless other factors.

But I think what we can all agree on is that if someone is having to spend time and energy, even just mental and emotional energy, fighting back against things like systemic racism, a history of trauma, or even intergenerational trauma, they're not going to have as much energy left over to provide care, and they're gonna be at a much greater risk for burnout.

So we need to be aware of that any time we're speaking with the population that has historically been victimized or oppressed. We need to be aware that they may not be as willing to engage right now, and we need to not expect them to try to solve these problems, because frankly, they have enough on their plate.

Any of us that have privilege need to use that to speak out for the changes in policies and the new programs, the new organizations that are needed to provide the support that's so desperately needed right now.

Alana Nur: Thank you so much, Bryan, and Erin, anything else that you would add?

Erin Emery-Tiburcio: Sure, just briefly, that in the current climate, the experience of racism can lead to decreased utilization of healthcare, so this is both for the caregiver and the care recipient, because healthcare is one of the historical perpetrators of racism.

So then on top of that you add fears of deportation for undocumented people, and many families will just likely go without care altogether. So this makes the virtual healthcare that many of us can provide that much more important, whether it's telephone--we're seeing a lot of concerns about technology, even if people don't have Internet or a smartphone. Even telephone, and reaching out, and the outreach that all of you do, doing all that we can to maximize feelings of safety and support when uncertainty reigns supreme right now. So thank you all for the work that you do.

Alana Nur: Thank you so much, Erin. All right, thank you so much. At this time, if you have additional questions, you can also email us at RIC@lewin.com. I'd like to bring your attention to our resource guide we compiled with help from today's speakers that we shared during the last webinar.

So you'll see it up here on the screen, we'll chat out the link, and you can also find it on our website. And we've also included a number of resources, including those ones that the speakers mentioned today and that we also chatted out during the session, and the final slide of this slide deck, which you can also find on our website.

Lastly, one more resource we wanted to share with you to assist with COVID-19 person-centered care planning comes from the National Center on Advancing Person-Centered Practices and Systems, a joint initiative between ACL and CMS. This tool may be particularly helpful for caregivers to plan for emergencies ahead of time, and ensure that the person they are caring for receives services aligned with their needs and preferences. You'll see the link here. It's also in the slide deck as well, and available for you.

The slides for today's presentation, a recording, and a transcript will be available on our website shortly. Thank you, everyone, so, so much for joining us today. Please complete our brief evaluation so that we can continue to deliver high-quality presentations. If you have any questions for us, please email us at RIC@lewin.com, and follow us on Twitter at [@Integrate_Care](https://twitter.com/Integrate_Care).

Again, thank you so much, Erin, Bryan, Kathy, and Carol, and to all of our audience participants, please stay safe and healthy, and thank you so much for your participation today.